DOCUMENT RESUME

ED 332 408 EC 300 270

TITLE	Adolescents with Chronic Illnesses--Issues for School Personnel. Second Edition. CYDLINE Reviews.
INSTITUTION	Minnesota Univ., Minneapolis. National Center for Youth with Disabilities.; Society for Adolescent Medicine, Granada Hills, CA.
SPONS AGENCY	Health Resources and Services Administration (DHHS/PHS), Rockville, MD. Office for Maternal and Child Health Services.
PUB DATE	Nov 90
CONTRACT	MCJ27361-010
NOTE	19p.
AVAILABLE FROM	National Center for Youth with Disabilities, University of Minnesota, Box 721-UMHC, Harvard St. at East River Rd., Minneapolis, MN 55455.
PUB TYPE	Reference Materials - Bibliographies (131) -- Reference Materials - Directories/Catalogs (132)
EDRS PRICE	MF01/PC01 Plus Postage.
DESCRIPTORS	Adolescents; *Chronic Illness; Demography; Educational Needs; Elementary Secondary Education; Family Involvement; Health Needs; Program Descriptions; *Psychological Characteristics; Resources; Social Influences

ABSTRACT

This resource guide covers the psychosocial and health concerns of adolescents with chronic illnesses. In a section titled "Bibliographic Information," the guide describes 12 books on general medical and social aspects, three resources on demographics, four resources on school issues, and 14 resources on psychosocial and family issues. A section titled "Training Materials" describes four videotapes and a booklet. A final section offers descriptions of six programs serving adolescents with chronic illnesses, providing program name, contact person name, address, telephone number, and abstract. (JDD)

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National Center for Youth with Disabilities

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CYDLINE Reviews:

Adolescents with Chronic Illnesses— Issues for School Personnel (Second Edition)

November, 1990

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A project of the:

Society for Adolescent Medicine
Adolescent Health Program

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The National Center for Youth with Disabilities is a collaborative project of the Society for Adolescent Medicine and the Adolescent Health Program at the University of Minnesota. The Center is supported through a grant from the Maternal and Child Health Bureau, Division of Services for Children with Special Health Needs, Department of Health and Human Services, #MCJ27361-010. The Center's mission is to raise awareness of the needs of youth with disabilities; foster coordination and collaboration among agencies, professionals, parents, and youth in planning and providing services; and provide technical assistance and consultation.

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National
Center for

Youth with Disabilities

The National Center for Youth with Disabilities (NCYD) is committed to raising awareness of the needs of adolescents and young adults with chronic illnesses and disabilities. In keeping with our mission, we have prepared this bibliography for classroom teachers and educational planners on the psychosocial and health concerns of adolescents with chronic illnesses. This information is intended to provide a brief overview of the issues and selected resources; it is not an exhaustive review. We hope that you will take the time to read through this bibliography and share it with anyone you believe would benefit from the information.

The information in this bibliography is drawn from the computerized database of the NCYD Resource Library. Other annotated bibliographies available free of charge from the NCYD Resource Library include:

- ☐ ***Transition from Pediatric to Adult Health Care for Youth with Disabilities and Chronic Illness***
- ☐ ***Promoting Decision–Making Skills by Youth with Disabilities—Health, Education, and Vocational Choices***
- ☐ ***An Introduction to Youth with Disabilities***
- ☐ ***Substance Use by Youth with Disabilities and Chronic Illnesses***
- ☐ ***An Introductory Guide for Youth and Parents***
- ☐ ***International Issues***

You can request specialized searches of the NCYD Resource Library on topics of your choosing simply by calling an NCYD information specialist. This person will then send you the requested information in a format similar to this bibliography. The database is also accessible, through menus or a command system, for interested individuals with their own computer and modem. Either way, you can easily receive current information on youth with disabilities that is specific to your particular needs and interests.

Thank you for your interest in the National Center for Youth with Disabilities. If you would like additional information on our Center, or would like to request information about the Resource Library, please call our information specialist at **1–800–333–6293** toll–free.

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I. BIBLIOGRAPHIC INFORMATION

A. GENERAL MEDICAL AND SOCIAL ASPECTS—BOOKS

BOOK	***Chronic Disorders in Adolescence.***
EDITOR	Smith MS;
SOURCE	John Wright–PSG: Boston: 426 pp.
DATE	1983
ABSTRACT	Smith and numerous colleagues, most from the University of Washington in Seattle, explore the spectrum of chronic disorders in adolescence with guidelines for the clinician who will provide general, continuous health care to patients with a variety of disorders, rather than highly specialized care to one subset of chronically ill youth. The text begins with reviews of physical and psychological development, the general effects of chronic illness on self, family, peer relations, and school, special educational and vocational considerations, the response to hospitalization and role of the specialized adolescent unit, death and dying in adolescence, and stress management techniques applicable to any disorder.

BOOK	***Chronic Illness and Disabilities in Childhood and Adolescence.***
EDITOR	Blum RW;
SOURCE	Grune and Stratton: NY: 474 pp.
DATE	1984
ABSTRACT	This edited volume stresses the psychological implications of chronic illness for adolescents. Most chapters discuss a single illness (e.g., cystic fibrosis, diabetes mellitus, epilepsy, sickle cell anemia, cancer, and renal disease) while others address issues common to adolescents across illness categories.

BOOK	***Chronic Illness During Childhood and Adolescence.***
AUTHOR	Garrison WT; McQuiston S;
SOURCE	Sage Publications: Newbury Park, CA: 160 pp.
DATE	1989
ABSTRACT	This book focuses on how chronic illnesses affect the psychological and social functioning of children and adolescents. Included is an overview of the critical issues in the assessment and treatment of youth with chronic illness, and case studies to highlight specific examples.

BOOK	***Chronic Illness and Disability—Families in Trouble Series, Volume 2.***
EDITOR	Chilman CS; Nunnally EW; Cox FM;
SOURCE	Sage Publications: Newbury Park, CA: 288 pp.
DATE	1988
ABSTRACT	This book contains 10 chapters covering the impact of chronic illnesses on families over the life span.

BOOK	***Children with Handicaps—A Medical Primer.***
AUTHOR	Batshaw ML; Perret YM;
SOURCE	Paul H. Brooks: Baltimore: 473 pp.
DATE	1986
ABSTRACT	Written in language appropriate for educators, this comprehensive text regarding medical aspects of children and youth with handicapping conditions provides in–depth studies of particular conditions. More than 130 detailed illustrations and a glossary are included.

BOOK	***Physical Disabilities and Health Impairment: An Introduction.***
EDITOR	Umbreit J;
SOURCE	Merrill Publishing Co., Columbus, Ohio: 484 pp.
DATE	1983
ABSTRACT	This book provides practical information about the care of youth with chronic illnesses or disabilities. Beginning with a review of normal anatomy and neurologic development, it reviews a wide range of orthopedic and neurological disorders and chronic illnesses in terms of a layman's description of the disorder, causes, diagnosis, and medical management. Photographs and diagrams are included. Lifestyle and educational issues are addressed as is the usefulness of a team approach.

BOOK	***Chronically Ill Children and Their Families.***
AUTHOR	Hobbs N; Perrin JM; Ireys HT;
SOURCE	Jossey–Bass: San Francisco: 406 pp.
DATE	1985
ABSTRACT	Discussion of the epidemiology of chronic illnesses; their effects on children, families, and communities; health, education, employment and social service needs; financing of care; professional development; directions for future research; professional ethics; and policy options.

BOOK	***Issues in the Care of Children with Chronic Illness.***
EDITOR	Hobbs N; Perrin JM;
SOURCE	Jossey–Bass: San Francisco: 953 pp.
DATE	1985
ABSTRACT	A major text in the field including discussions of basic concepts of chronic illness; epidemiology, demography, and representative conditions; populations with special needs; provision of services and professional training; educational and vocational issues; programs and organizations serving chronically ill children and their families; and economic considerations. 42 chapters.

BOOK	***Understanding the Child with a Chronic Illness in the Classroom.***
EDITOR	Fithian J;
SOURCE	Oryx: Phoenix, AZ: 245 pp.
DATE	1984
ABSTRACT	Intended for teachers with little background in health, this book describes 13 chronic illnesses (e.g., cancer, cystic fibrosis, diabetes mellitus, congenital heart defect, hemophilia, epilepsy, asthma, rheumatic heart disease, juvenile rheumatoid arthritis, and muscular dystrophy) and their impact on children in school.

BOOK	***Handicapped Children and Youth. A Comprehensive Community and Clinical Approach.***
AUTHOR	Wallace HM: Biehl RF; Oglesby AC; et al.;
SOURCE	Human Sciences Press: New York: 378 pp.
DATE	1987
ABSTRACT	Professionals from many disciplines contributed to this text designed for a broad audience of professionals. The first chapters describe definitions of disability, the impact on children and families, historical approaches to services, and current services within public programs and voluntary organizations. Subsequent chapters address legal rights, advocacy, early identification and screening, evaluation and management, nutritional needs, oral health, the role of various professionals, special education, sexuality, respite care, transportation, and state and community programs. The last third of the book includes overviews of many handicapping conditions. This could be a useful introductory text for students in many disciplines who will deal with children and disabilities.

BOOK	***Medical Problems in the Classroom: The Teacher's Role in Diagnosis and Management (2nd Edition).***
EDITOR	Haslam RHA; Valletutti PJ;
SOURCE	Pro-Ed: Austin, TX: 481 pp.
DATE	1985
ABSTRACT	Excellent textbook designed to help educational personnel understand and adapt to a broad spectrum of childhood health problems. The material is well-organized, well-illustrated, and quite readable. Initial chapters review the role of teachers in early diagnosis and referral in prevention of disabilities. Chapters are devoted to normal growth and development and various disabilities.

BOOK	***The Unexpected Minority: Handicapped Children in America.***
AUTHOR	Gliedman J; Roth W;
SOURCE	Harcourt, Brace, Jovanovich: NY: 525 pp.
DATE	1980
ABSTRACT	This book, considered a landmark in the field, addresses the problems of children and youth with disabilities from a social/civil rights perspective rather than using a medical model. Critical research is entwined with anecdotes and interviews. In addition to discussing the social and psychological aspects of handicapping conditions, the authors include a section on services for children and employment and maturation issues for young adults.

B. DEMOGRAPHICS

AUTHOR Gortmaker SL: Sappenfield W;
TITLE **Chronic childhood disorders: Prevalence and impact.**
SOURCE *Pediatr Clin North Am* 1984 Feb; 31(1): 3–18.

ABSTRACT Review a wide range of chronic illnesses with an emphasis on areas of change and their implications.

AUTHOR Newacheck PW; Budetti PP; Halfon N;
TITLE **Trends in activity–limiting chronic conditions among children.**
SOURCE *Am J Public Health* 1986 Feb; 76(2): 178–84.

ABSTRACT Analysis of data from the National Health Interview Survey indicating an increase in prevalence of activity–limiting chronic conditions among children under 17 years from 1.8% in 1960 to 3.8% in 1981, with approximately 40% of the increase occurring before 1970. After 1970, the increase in prevalence was due to increases in the less severe forms of limitations.

AUTHOR Garell DC;
TITLE **Beyond survival of the fittest: Adolescents with chronic illness in the Year 2000.**
BOOK SOURCE *Proceedings of the Health Futures of Adolescents Conference.* National Center for Youth with Disabilities, Box 721 University of Minnesota Hospital and Clinic, Harvard St. at E. River Rd., Minneapolis, MN 55455.
DATE 1986

ABSTRACT Discussion of epidemiologic and service delivery issues that affect planning, including technology, in–home services, mainstreaming, support systems, long–term planning, parental involvement, self–help efforts, and changes in the marketplace.

C. SCHOOL ISSUES

AUTHOR Weitzman M; Walker DK; Gortmaker S;
TITLE **Chronic illness, psychosocial problems, and school absences.**
SOURCE *Clin Pediatr* 1986 Mar; 25(3): 137–41.

ABSTRACT In this study, children age 6–17 years with chronic illness were found to miss more school than children without chronic illness. This difference was substantial among those with asthma, permanent stiffness, mental retardation, arthritis, seizures, and cerebral palsy. Even children without functional impairments missed significantly more school than controls. Psychosocial problems were associated with more missed school days, especially problems associated with learning and school, particularly when combined with a chronic illness. Poverty was also strongly associated with missing school.

AUTHOR Fowler MG; Johnson MP; Atkinson SS;
TITLE **School achievement and absence in children with chronic health conditions.**
SOURCE *J Pediatr* 1985 Apr; 106(4): 683–7.

ABSTRACT Data were collected for children and adolescents with the following conditions: arthritis, blood disorder, cardiac disease, chronic bowel disease, chronic lung disease, cystic fibrosis, diabetes, epilepsy, hemophilia, sickle cell disease, and spina bifida. Achievement scores were lower and numbers of days absent were higher for children with chronic illnesses. Achievement scores did not correlate with number of days absent, but rather with socioeconomic factors and specific health condition (spina bifida, sickle cell disease, and epilepsy).

AUTHOR Walker DK;
TITLE **Care of chronically ill children in schools.**
SOURCE *Pediatr Clin North Am* 1984 Feb; 31(1): 221–33.

ABSTRACT Discussion of educational placement, school services, and the pediatrician's role in the schools. In view of regulations requiring that schools accommodate children with a wide variety of chronic illnesses, this article identifies the major issues that must be addressed by schools and proposes guidelines for appropriate school care. Required services are described: support therapies (speech/language, occupational, and physical); schedule modifications; modified physical education; transportation; building accessibility; toileting/lifting assistance; counseling services (school, career, and personal); and school health services (administration of medications, implementation of medical procedures, emergency preparations, case coordination).

AUTHOR Chekryn J; Deegan M; Reid J;
TITLE **Normalizing the return to school of the child with cancer.**
SOURCE *J Assoc Pediatr Oncol Nurses* 1986; 3(2): 20–4, 34.

ABSTRACT This article draws upon information derived from interviews with parents, teachers, and 10–16 year–old children with cancer. All perceived school as a normalizing influence while describing the difficulties of reentry. Ways in which health professionals and teachers can foster positive reentry are discussed. Strategies are suggested which can help children keep up academically when unable to attend classes.

D. PSYCHOSOCIAL AND FAMILY ISSUES

AUTHOR Perrin EC; Gerrity PS;
TITLE **Development of children with a chronic illness.**
SOURCE *Pediatr Clin North Am* 1984 Feb; 31(1): 19–31.

ABSTRACT Using Piagetian and Ericksonian developmental frameworks, this article discusses normal growth and development from infancy through adolescence. Each stage is examined in terms of the ways in which a chronic illness can interfere with the social, educational, and emotional aspects of development.

AUTHOR Beck AL; Nethercut GE; Crittenden MR; et al.;
TITLE **Visibility of handicap, self–concept, and social maturity among young adult survivors of end–stage renal disease.**
SOURCE *J Dev Behav Pediatr* 1986 Apr; 7(2): 93–6.

ABSTRACT This study found visibility of handicap to be inversely related to identity, stability, social maturity, and self–esteem. All patients had undergone transplant surgery at least once, but seven remained on dialysis. The researchers also suggest that time may contribute to improved adjustment due to the finding of a positive correlation between self–esteem and years since last transplant.

AUTHOR Orr DP; Weller SC; Satterwhite B; et al.;
TITLE **Psychosocial implications of chronic illness in adolescence.**
SOURCE *J Pediatr* 1984 Jan; 104(1): 152–7.

ABSTRACT This is an eight–year follow–up of 144 youth age 13–22 years with a chronic illness. Health status at follow–up correlated with eight psychosocial variables: planning for the future, engaging in family activities, dating, possession of a driver's license, talking with parents, satisfaction with family life, school enrollment, and school adjustment. While most of the adolescents with chronic illness showed normal adjustment, those who experienced a resulting impairment were most at risk for problems in the above areas.

AUTHOR Dodrill CB; Clemmons D;
TITLE **Use of neuropsychological tests to identify high school students with epilepsy who later demonstrate inadequate performances in life.**
SOURCE *J Consult Clin Psychol* 1984 Aug; 52(4): 520–7.

ABSTRACT The actual abilities of individuals with epilepsy, particularly language abilities, were found to predict later adjustment and independent living better than were measures of emotional adjustment.

AUTHOR Alpern D; Uzark K; Dick M;
TITLE **Psychosocial responses of children to cardiac pacemakers.**
SOURCE *J Pediatr* 1989 Mar; 114(3): 494–501.

ABSTRACT Compared to healthy youth and those with congenital heart disease but no pacemaker, youth with pacemakers were not found to differ on measures of trait anxiety, self–competence, and self–esteem. However, the pacemaker group did perceive a decreased sense of personal control and autonomy. They seem to have minimal fear of death and dying, and believe they are quite similar to their peers. Nonetheless, the two comparison groups did perceive differences in youth with pacemakers regarding social and emotional factors.

AUTHOR Court S; Sein E; McCowen C; et al.;
TITLE **Children with diabetes mellitus: Perception of their behavioural problems by parents and teachers.**
SOURCE *Early Hum Dev* 1988 Mar; 16(2–3): 245–52.

ABSTRACT When youth with diabetes were compared to healthy youth, parents and teachers were more likely to see the youth with diabetes as being disturbed, although parents were less likely to perceive disturbance than were teachers.

AUTHOR Morgan SA; Jackson J;
TITLE **Psychological and social concomitants of sickle cell anemia in adolescents.**
SOURCE *J Pediatr Psychol* 1986 Sep; 11(3): 429–40.

ABSTRACT Study of 24 patients compared with 24 healthy adolescents supporting the hypothesis that affected adolescents are at an increased risk for adjustment problems. This study examined measures of: body satisfaction, depression, and social withdrawal. In all three areas, adolescents with sickle cell anemia were found less well adjusted than matched controls. The authors assert that, to some extent, these findings may reflect a realistic response to life circumstances. Studies of adolescents with similar types of illness have yielded similar findings. The authors suggest disease–related variables (growth retardation, delayed puberty, limited physical capacity, and academic underachievement) may underlie their findings.

AUTHOR Smith MS; Gad MT; O'Grady L;
TITLE **Psychosocial functioning, life change, and clinical status in adolescents with cystic fibrosis.**
SOURCE *J Adol Health Care* 1983 Dec; 4(4): 230–4.

ABSTRACT Results indicate generally favorable adjustment and self-esteem of adolescents with cystic fibrosis with the majority at grade level participating in physical education classes and planning for college and/or career. These adolescents reported a relatively external locus of control and adequate social support from friends and family. Overall, a measure of life event changes found these adolescents to be comparable to the norm, but higher scores were found for those adolescents with a higher level of health impairment.

AUTHOR Smith G;
TITLE **A patient's view of cystic fibrosis.**
SOURCE *J Adol Health Care* 1986 Mar; 7(2): 134–8.

ABSTRACT An eloquent and thought–provoking account of a young man's experience of life with cystic fibrosis.

AUTHOR Zeltzer L; Kellerman J; Ellenberg L; et al.;
TITLE **Psychologic effects of illness in adolescence. II. Impact of illness in adolescents—Crucial issues and coping styles.**
SOURCE *J Pediatr* 1980 Jul; 97(1): 132–8.

ABSTRACT Comparison of 345 healthy adolescents and 168 adolescents with chronic illnesses. The psychologic normalcy found indicates a need for psychosocial rather than intrapsychic rehabilitation. Adolescents with a major chronic illness did not differ from healthy peers in the total perceived impact of illness on their lives. Adolescents perceived the areas of illness impact differently according to the type of illness they had. Females were more concerned with physical appearance than males were.

AUTHOR Woodhead JC; Murph JR;
TITLE **Influence of chronic illness and disability on adolescent sexual development.**
SOURCE *Semin Adol Med* 1985 Sep; 1(3): 171–6.

ABSTRACT Discussion of sexual issues with a psychosocial emphasis relating to chronic illness and disability by developmental level.

AUTHOR Margalit M; Cassel–Seidenman R;
TITLE **Life satisfaction and sense of coherence among young adults with cerebral palsy.**
SOURCE *Career Dev Excep Indiv* 1987 Spring; 10(1): 42–50.

ABSTRACT Results indicate limited life options for these 34 young adults (mean age = 24.4 years) who, nonetheless, report relatively high life satisfaction. Regression analysis found that: 1) a feeling of meaningfulness; 2) the amount of support and guidance received; and 3) feelings of manageability and control accounted for 66% of the variance in life satisfaction.

AUTHOR Sinnema G; Bonarius HC; Van der Laag H; et al.;
TITLE **The development of independence in adolescents with cystic fibrosis.**
SOURCE *J Adol Health Care* 1988 Jan; 9(1): 61–6.

ABSTRACT Compared to adolescents who had asthma or who had short stature or who were healthy controls, adolescents with cystic fibrosis were found to show less responsibility for their own body hygiene, to have a delay in intimacy and sexuality, and to take less part in social activities outside the home. There were minimal or no differences between ill and healthy adolescents for four factors. The correspondence between the chronically ill and the healthy adolescents prevailed over the differences. The main differences could be interpreted in terms of realistic coping with the illness and maintaining hope for the future.

AUTHOR	Gunther MS;
TITLE	**Acute–onset serious chronic organic illness in adolescence: Some critical issues.**
SOURCE	*Adolesc Psychiatry* 1985; 12: 59–76;
ABSTRACT	This article discusses psychological impact of serious, chronic organ disease. Enumerates common reactions to serious illnesses (acute or chronic): affect (anxiety, guilt, surprise, resentment, depression); fear (of separation, of the unknown, of pain, of treatment, of the future); regression; introversion; attitudes toward health professionals (dependence, idealization, angry disappointment, resentment); aggression; defensiveness. Describes specific adolescent adaptations of these reactions. Discusses normative development as it relates to chronic illness. Concludes with suggestions of factors which practitioners can influence.

II. TRAINING MATERIALS

TITLE	**School: Obstacle or Opportunity?—Coping With with Chronic Illness in the Secondary Classoom**
ADDRESS	Hematology/Oncology Division, Children's Hospital Medical Center, Elland and Bethesda Avenues, Cincinnati, OH 45229
PHONE	513/559–4266
DATE	1984
ABSTRACT	*"School: Obstacle or Opportunity"* is a 25–minute videotape aimed at helping secondary school staffs cope with chronic illness in the classroom. Interviews are done with principals and educators themselves who have dealt with chronic illness effectively on a secondary level. Practical tips are offered to school staffs in dealing with teenagers with cancer, epilepsy, juvenile arthritis, and other chronic illnesses. Cancer is used as a model for how students and teachers cope in the classroom, but the fact that the issues are the same for teenagers with other chronic illnesses is strongly emphasized. Audiovisual program won awards from the American Cancer Society and the Association for the Care of Children's Health. (Rental: $50/week; Purchase: $200)

TITLE	**Practically Speaking**
ADDRESS	Hematology/Oncology Division, Children's Hospital Medical Center, Elland and Bethesda Avenues, Cincinnati, OH 45229
PHONE	513/559–4266
DATE	1988
ABSTRACT	*"Practically Speaking"* is a small booklet aimed at helping school staffs feel more comfortable in the classroom in dealing with chronic illness. Practical pointers are offered as a way of acknowledging that teachers often have many tasks to juggle in the classroom, and so this booklet helps to make confronting chronic illness less threatening and overwhelming. (Available at no cost.)

TITLE	**Coping With Cancer: The Middle School Years**
ADDRESS	555 West 57th Street, New York, NY 10019
PHONE	212/582–8820
DATE	1983
ABSTRACT	Because children aged 12–14 gain so much of their support from peers, this 36–minute videotape opens the door on three young patients in a therapeutic group setting. Here the viewer gains vital insights difficult to acquire in any other way: how these children felt when their cancer was diagnosed; when they returned to school; when peers asked questions; when friends in the hospital died; when their treatments caused pain, hair loss, fear; when they were teased or friends failed to understand. (Rental price: $60; Purchase: $200)

TITLE	**Coping With Cancer: The High School Years**
ADDRESS	555 West 57th Street, New York, NY 10019
PHONE	212/582–8820
DATE	1983
ABSTRACT	At a difficult age, with a complicated disease, six courageous teenage patients shed light on the range of their emotions as they encounter their peers, teachers, and parents; as they fight to maintain and increase their independence, a struggle made more difficult by overly protective, worried adults; and as they discover one of life's miracles—that their fight with cancer has strengthened and enriched them. (This 37–minute videotape is available for $60 rental or $200 purchase.)

TITLE	**Don't Freeze Me Out**
ADDRESS	3450 Slade Run Drive, Falls Church, VA 22042
PHONE	1–800–342–4336
DATE	1987
ABSTRACT	*Don't Freeze Me Out* features members of the Adolescent Oncology Support Group at Johns Hopkins Hospital in Baltimore, Maryland. This 16–minute videotape explores their feelings and experiences on returning to school after chemotherapy, bone marrow transplants, surgery, or other treatments for cancer. The message of the tape is targeted at fellow students, teachers, and administrators who are ignorant or callous toward their fragile state after the treatment. The video is part documentary/part music video, with an original song, to appeal to teenagers. (This is available for $195 purchase plus postage and handling; 3–day rental is $50.)

III. PROGRAM DESCRIPTIONS

NAME	**Comprehensive Pediatric Rheumatology Center, Prevocational Training Program for Adolescents with Rheumatic Diseases and Other Chronic Illnesses**
CONTACT	Patience White, M.D. & Margaret Gaumond, M.S.W.
ADDRESS	Children's Hospital National Medical Center, 111 Michigan Avenue, N.W., Washington, D.C. 20010
PHONE	202/745–3203
ABSTRACT	The goal of the Comprehensive Pediatric Rheumatology Center's Prevocational Training Program is to improve vocational readiness in adolescents, ages 12–19, with chronic illnesses. The program includes the components of SERVICE, including assessment, job placement, and the development of a vocational resource directory; EDUCATION, including prevocational conferences for adolescents and their families, educational advocacy, courses, and the Next–Steps Planning for Employment course; EVALUATION/RESEARCH, including the expansion of computerized database to include vocational maturity and job experience variables.

NAME	**The Adolescent Day Hospital of Chronically Ill Adolescents/ The First State School**
CONTACT	Janet P. Kramer, M.D., Director of Adolescent Medicine
ADDRESS	Medical Center of Delaware, Christiana Hospital, P.O. Box 6001, 4C–4107, Newark, DE 19718
PHONE	302/733–4107
ABSTRACT	The Adolescent Day Hospital for Chronically Ill Adolescents, a first of its kind in the U.S., is an educational–medical program co–sponsored by the Medical Center of Delaware and the Delaware Department of Instruction to promote intellectual, social, and emotional growth for homebound adolescents in sixth through 12th grade who are too ill to attend regular school. On school days year round, the adolescents are transported to and from the Medical Center and home on special buses and receive their medical care, e.g., renal dialysis, IV's, chemotherapy, physical therapy, etc., while attending an educationally excellent program which includes peer support, family support, psychological services, and career transition planning.

NAME	**Dialysis Unit for Pennsylvania State University Students**
CONTACT	John McQueary, Administrator
ADDRESS	3901 S. Atherton Street, Suite 5, State College, PA 16801
PHONE	814/466–7911
ABSTRACT	This is the first facility anywhere to provide multi–level support to young people with kidney disease who want to pursue their education. The program helps them prepare for careers and develop independence in managing their daily lives and their illness. Housed in off–campus apartments, the unit offers special personnel and facilities. A resident counselor and an educational coordinator provide counseling and academic assistance. A dietician helps students plan meals that fit their renal diets. A physician and a head dialysis nurse oversee medical care. Students also benefit from enrolling in special courses at the Pennsylvania State University.

NAME	**Diabetes Project Unit**
CONTACT	Janet Silverstein or Gary Geffken
ADDRESS	University of Florida, Box J–296 JHMHC, Gainesville, FL 32610
PHONE	904/392–2708
ABSTRACT	This is a state–funded residential center within the hospital of the University of Florida. This program was designed for youths unable to cope with diabetes, requiring frequent hospitalization, or with multiple school absences or school failure. The youth attend public school and live in a dorm–like setting. They are supervised by parent surrogates 24 hours a day. The youths, in addition to participating in public school activities, also have diabetes education sessions as well as twice weekly individual psychotherapy and weekly family counseling. Group therapy sessions take place once a week. Medical rounds formally take place once a week, but medical intervention is applied when indicated.

NAME	**University of South Florida Diabetes Center–Children's Diabetes Program**
CONTACT	John I. Malone, M.D.
ADDRESS	University of South Florida, College of Medicine, 12901 Bruce B. Downs Blvd., Box 45, Tampa, FL 33612
PHONE	813/974–4360
ABSTRACT	The Center is a treatment and education facility which serves patients with diabetes and other endocrine disorders. It provides model care and treatment with the emphasis on the "team approach." The team consists of staff, the patients, and their family members. Education is provided in clinic and through special workshops geared to all ages. Workshops for parents are also provided. The adolescent workshops are geared to the problems that they face, including peer pressure, communication, drugs and substance abuse, and sexuality. In–depth education of survival skills is provided for newly diagnosed patients and their families in the outpatient facility. This education can last 2–5 days. Nutrition workshops are also provided.

NAME	**Adolescent Trauma Recovery Program**
CONTACT	Grant Butterbaugh, Ph.D.
ADDRESS	University of Maryland Hospital, Department of Pediatrics, 22 S. Greene Street, Baltimore, MD 21201
PHONE	301/328–4865
ABSTRACT	The ATRP is an interdisciplinary program. Several professionals work together to offer comprehensive rehabilitative care for teens with head injury. Medical, psychological, and educational needs are assessed. Depending on the individual, the following services are available: adolescent medical care, psychology, neuropsychology, adolescent social work, nutrition, short–term inpatient care, and speech therapy. Addressing the varied needs of injured teens through this comprehensive approach is the primary goal of ATRP. Further, ATRP serves as a liaison between family and the school to facilitate school re–entry. ATRP aims for the eventual reintegration of the teen into family, school, and community life.

CYDLINE Reviews

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National Center for Youth with Disabilities/Society for Adolescent Medicine

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